Dementia In-Sight

A review of dementia and dementia provision in Hull
January 2018

Commissioned by NHS Hull Clinical Commissioning Group
Reviewer: Wayne Goddard, RGN, RMN, Ba Ed (Hons), MSc.
Coming together is a beginning; keeping together is progress; working together is success.

Henry Ford.
Foreword

As the Hull City Council Cabinet member with the portfolio for Public Health and Adult Social Care, I welcome this review of dementia provision in Hull and commend our CCG partners for recognising the need to perform this review. Together we can make a real difference to the lives of people living with dementia and their carers in Hull.

As a Mental Health champion for the city I am particularly pleased with the recognition of the need to support carers better. That we recognise the invaluable input each carer makes and, as a partnership, that we appreciate and value the skills, experience and commitment of carers which this review clearly recognises. We now need to work together to ensure we support carers so they can continue to care well.

I look forward to working with Council colleagues and our partners to bring about a sustainable transformation of dementia provision in Hull.

Councillor Gwen Lunn
Hull County Council
Portfolio Holder for Public Health and Adult Social Care
As a working GP in Hull, and for Hull Clinical Commissioning Group as the Primary Care lead in Dementia, I wholly embrace this review of the dementia services across Hull, in particular pertaining to how we can improve the post diagnostic services in Hull and as part of this post diagnostic support develop meaningful care plans for patients. This is an area of care I feel passionate about. Care plans could positively impact on people’s experience of health and social services by facilitating the sharing of information between professionals, improving access to the correct services at the correct time and providing a named professional to coordinate patient’s needs. One of the key themes from this review report is how we need to continue to improve how we work together to provide the best services possible. I look forward to working in partnership with all organisations involved in the delivery of dementia services to take these recommendations forward.

Dr Angharad (Hari) Symes
GP and CCG Primary Care Lead for Dementia

As Hull Dementia Patron I am so pleased that this review has taken place and I thoroughly support its findings. Dementia for too long has been in the shadows and it is great to see the people of Hull working together to care and support this vulnerable and disadvantaged group of people. What an achievement it will be to say Hull is truly Dementia Friendly.

John Godber
OBE & Hull Dementia Patron
**Executive summary**

The need for people to receive a timely diagnosis and better quality care and support forms part of the priorities outlined in the Prime Minister’s Challenge on Dementia 2020\(^1\). The Challenge sets out the UK Government’s long term strategy for transforming dementia care within the UK. The strategy’s aspirations include improving diagnosis, assessment and care for people with dementia. The aims of the strategy include that by 2020, all people with dementia will have equal access to a diagnosis, all NHS and Social Care staff will receive training on dementia appropriate to their role, and every person diagnosed with dementia will receive meaningful care.

Hull Clinical Commissioning Group (CCG) like many other CCGs and service providers are seeking ways to improve the quality and costs associated with providing dementia services. Current and predicted increases in demand, improved access and changes in workforce capacity and capability, have led Hull CCG’s to review their model of service provision.

The aim of this review is to assist Hull CCG and its partners to understand the current position regarding dementia and dementia provision in the City and understand how this position considering legislation, policy, guidance and dementia best practice.

Through extensive and multi method engagement and involvement this review presents Hull’s position against the national context of dementia and utilises the Well Pathway for Dementia as a framework to make recommendations for consideration by the CCG and partners. These recommendations have been produced as a table for ease and can viewed in Appendix A.

Hull’s success in delivering an excellent dementia diagnostic rate has in turn produced a new challenge and one of how people with dementia and their carers are cared for and supported effectively post diagnostically.

The review presents clearly “what” can and should be commissioned and suggests “how” this could be delivered through an Accountable Care Partnership considering the backdrop of there being no new funding, reducing resources, increasing demand and higher expectations. Ensuring timely and equitable access to a diagnosis and effective equitable access to post diagnostic care and support will only be delivered through successful integration, collaboration and partnerships.
Introduction

The need for people to receive a timely diagnosis and better quality care and support forms part of the priorities outlined in the Prime Minister’s Challenge on Dementia 2020. The Challenge sets out the UK Government’s long term strategy for transforming dementia care within the UK. The strategy’s aspirations include improving diagnosis, assessment and care for people with dementia. The aims of the strategy include that by 2020, all people with dementia will have equal access to a diagnosis, all NHS and Social Care staff will receive training on dementia appropriate to their role, and every person diagnosed with dementia will receive meaningful care.

Since the 2006 NICE Clinical Guideline 42 (CG42) Dementia: supporting people with dementia and their carers in health and social care was developed, key new legislation has been implemented. The Mental Capacity Act 2005 created new systems for people living with dementia, their family members and carers, and health and social care staff, to make decisions about care. The Care Act 2014 created a new legislative framework for adult social care, and also gives carers a legal right to assessment and support. In support of the PMs Challenge on dementia, the Government’s Mandate to the NHS outlines an objective to make measurable progress towards being among the best in Europe at diagnosing, treating and caring for people with dementia.

Many Clinical Commissioning Groups (CCGs) and service providers are seeking ways to improve the quality and costs associated with providing dementia services. Current and predicted increases in demand, improved access and changes in workforce capacity and capability, have led several CCG’s to review their model of service provision.

The aim of this review is to assist Hull CCG and its partners to understand the current position regarding dementia and dementia provision in the City and understand how this position compares to legislation, national policy, guidance and what is regarded as current best dementia practice. This understanding will assist the informed consideration of recommendations and support effective commissioning decisions.

The target audience for this review are commissioners, although people providing dementia services along with people with dementia, their carers and wider family and supporting structures may also find the information useful.

2. https://www.nice.org.uk/guidance/cg42
The assessment of Hull’s dementia provision has been delivered through a comprehensive multi-method approach. Extensive and meaningful engagement and involvement of all dementia stakeholders was performed through one to one and group interviews, site and service visits, a mapping exercise, a person with dementia and carer focused Electronic Survey and a person with dementia, carer and wider stakeholder engagement event. In addition to these methods open lines of communication to the reviewer, through email and telephone, were offered to Hull citizens and all dementia stakeholders.

A Review Briefing (Appendix B) gives further detail on the review scope, approach, outputs, methodology, key milestones and risks and constraints. The Review work plan is shown as Appendix C and the Reviewers biography is shown as Appendix D.

This review utilised the Well Pathway for Dementia\(^5\) as a framework for assessment and comparison to enable practical recommendations and options for the CCG and its partners to consider. This review should not be seen as an all-encompassing or a stand-alone review. The review must be read and considered in association with and set against the context of legislation, national strategy, policy and local assessments and delivery plans, in particular:

### National:

- Nice Guidance CG42 (new Guidance due 2018) and Quality Standards.
- Prime Ministers Challenge on Dementia 2020.
- Prime Ministers Challenge on Dementia 2020 Implementation Plan\(^6\).
- Implementation guide and resource pack for dementia care\(^7\).

### Local:

- Humber Coast and Vale Sustainability and Transformation Partnership (HCV STP)\(^8\).
- Humber Coast and Vale, Hull Place Delivery Plan\(^9\).
- Hull’s Joint Strategic Needs Assessment (JSNA) and Toolkit 7, Older People\(^10\).
- Hull Better Care Fund (BCF) Integration Plan 2017-2019\(^11\).

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The overall theme for this review is one of Quality Improvement; to make the care and support of people affected by dementia better. The NHS Change Model\textsuperscript{12} and the evidence and tools within the Dementia Services Development Centre\textsuperscript{13} are a key feature of the recommendations for consideration. Further additional resources utilised for this review can be found in Appendix G.

Underpinning the theme of Quality Improvement are the equality and health inequalities legal duties for commissioners\textsuperscript{14} The review takes into account the duties under the Equality Act 2010\textsuperscript{15} and with regard to reducing health inequalities, duties under the Health and Social Care Act 2012\textsuperscript{16}.

Building on the Dementia Declaration\textsuperscript{17}, the review will also utilise the Dementia Statements\textsuperscript{18} produced by the Dementia Action Alliance. The original statements commencing with “I” have been changed to “we” to also account for the needs of carers and families of people living with dementia.

1. “We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it”.

2. “We have the right to continue with day-to-day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness”.

3. “We have the right to an early and accurate diagnosis, and to receive evidence based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live”.

4. “We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future”.

5. “We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part”.

\textsuperscript{12}https://www.england.nhs.uk/sustainableimprovement/change-model/
\textsuperscript{13}http://dementia.ie/
\textsuperscript{14}https://www.england.nhs.uk/about/equality/equality-hub/legal-duties/
\textsuperscript{15}https://www.gov.uk/guidance/equality-act-2010-guidance
\textsuperscript{16}http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted
\textsuperscript{17}https://www.dementiaaction.org.uk/nationaldementiadeclaration
\textsuperscript{18}https://www.dementiaaction.org.uk/news/23236_news.launching.the.dementia.statements
Dementia - a national context

Dementia is a progressive, variable and largely irreversible condition that covers a wide range of symptoms. It is characterised by widespread impairment of mental function, including some or all of the following:\(^{19}\):

- memory loss
- communication difficulties and sensory impairment
- disorientation
- personality change
- difficulties with activities of daily living
- self-neglect
- behaviour that is out of character (for example, sleep disturbance or sexual disinhibition)

Alzheimer’s disease accounts for around 60% of cases with 20% of cases being vascular dementia. However, increasing numbers of “mixed type” dementias are being recorded and it is estimated vascular disease is a contributory factor of 50% of cases.

A report published by the Alzheimer’s Society\(^{20}\) found that in 2013 there were approximately 815,000 people living with dementia in the UK. Alzheimer’s Research\(^{21}\) estimate there are now 850,000 people now living with dementia in the UK with 520, 000 having a formal diagnosis. The number of people living with dementia in the UK is expected to increase to 1,143,000 by 2025 and 2 million by 2050 if current trends continue.

According to the National Dementia and Antipsychotic Prescribing Audit\(^{22}\) (2012), there were approximately 31,000 people newly diagnosed with dementia in England in 2011. This is an increase of 8% between 2006 and 2011.

According to the Alzheimer’s Society, dementia is now the most feared disease for people aged fifty five and over. Dementia mainly affects older people and after the age of 65 the likelihood of developing dementia increases every 5 years. Younger people can also be affected by dementia. There are estimated to be 40,000 people under 65 living with dementia with the number of cases of dementia remaining static and proportionate to the population.

\(^{19}\) https://www.nice.org.uk/guidance/cg42
\(^{21}\) https://www.dementriastatistics.org/statistics-about-dementia/prevalence/
\(^{22}\) https://digital.nhs.uk/catalogue/PUB06624
The risk of developing Mild Cognitive Impairment (MCI) increases with age and though difficult to calculate some research suggests up to 20% of over 65’s will have MCI. Although MCI is more prevalent with Parkinson’s disease some research suggests up to 60% of MCI cases will go on to develop dementia\textsuperscript{23}.

In 2011 there were 25,000 people with dementia from Black, Asian and Minority Ethnic (BAME) groups however this number is expected to double to 50,000 by 2026 and to rise to over 172,000 by 2051. BAME groups are more prone to the vascular risk factors of dementia\textsuperscript{24}.

People living with Down’s Syndrome and learning disability have an increasing life expectancy and have an increased risk of developing dementia. 1 in 3 people with Downs Syndrome will develop dementia in their 50’s \textsuperscript{25}.

In 2015 dementia became the leading cause of death in England and Wales accounting for 11.6% of all deaths registered.

The Alzheimer’s Society report found that in 2013 the total cost of dementia in the UK was estimated to be £26.3 billion. Of this, approximately £4.3 billion consists of health care, and approximately £10.3 billion consists of social care. The remaining £11.6 billion accounts for estimated unpaid care contributions.

Two thirds of hospital beds are occupied by older people; two thirds of these will have some cognitive impairment; with 90% of those having dementia. People with dementia attending A&E are more likely to be admitted and if they are admitted have a longer length of stay than those people with similar health needs but without dementia. People with dementia are more likely to be readmitted than those without dementia.

People with dementia in hospital are more likely to die than those with those with the same health needs but without dementia. People with dementia in hospital are more at risk of incidents such as falls.

\textsuperscript{23} \url{https://patient.info/doctor/mild-cognitive-impairment}
\textsuperscript{24} \url{https://www.england.nhs.uk/wp-content/uploads/2015/01/transform-care-next-}
\textsuperscript{25} \url{https://www.alzheimers.org.uk/info/20007/types_of_dementia/37/learning_disabilities_and_dementia}
Approximately two thirds of residential beds are occupied by people with dementia and a third of people with dementia live at home. The vast majority of those with dementia living at home have a carer. There are around 6.5 million carers (1 in 8 adults) in the UK. This is predicted to increase to 9 million by 2037. Carers save the economy £132b a year with 1 in 5 carers having to give up employment to care. Over 1.3m carers provide over 50 hours of care a week and 625,000 report physical and mental health issues as a consequence of caring. There are 670,000 carers (80% of estimated dementia cases) of people living with dementia saving the economy £11b a year. The days lost at work as a result of caring duties is estimated to cost the business and service economy £3b with the people leaving work to care set to rise from 50,00 to 83,00 by 2030.

72% of survey respondents reported living with another medical condition or disability as well as dementia. The range varied considerably but the most common ones were arthritis, hearing problems, heart disease or physical disability. Diabetes doubles the risk of dementia and cardiovascular disease increases the risk by one third. People living with dementia are 30 times more likely to develop delirium. 100,000 people living with dementia have sight loss and deafness is a risk factor.

27 http://tide.uk.net/
**Dementia – Hull context**

The number of people living with dementia is intrinsically linked to population size, age, vascular and quality of life factors and is often co-terminus with other disease and long-term conditions. By understanding the current and predicted demographic position in Hull will assist the understanding of the current and predicted dementia position in Hull.

According to the Hull Integration (BCF) Plan Hull has a population of approximately 258,000 people set to rise to 261,000 by 2025. Hull has a current GP practice list size of c296,000 from the neighbouring towns and villages on the border with the East Riding of Yorkshire. Hull CCG and Hull City Council boundary is co-terminus, whilst the GP list size is 30,000 higher than the population.

The percentage of the population aged 65+ years varies markedly across the 23 wards in Hull ranging from 6.9% in Newland and 8.7% in King’s Park wards to 22.1% in Beverley and 23.3% in Ings wards. The total number of people aged 65+ years in each ward varies from 788 in Newland and 969 in King’s Park wards to over 2,000 people in Ings, Longhill, Sutton, Holderness, Boothferry, Derringham and Pickering wards (with an estimated 2,756 people aged 65+ years living in Ings ward compared to 2,258 in Pickering ward which has the second highest estimated number). In Ings ward, it is estimated that there are around 450 people aged 85+ years, with around 150 people aged 90+ years.

Life expectancy in Hull is lower than the UK average (77 years for men, 80 years for women). The percentage aged 65+ years out of the total population is currently estimated to be around 15% but is expected to increase to 19% by 2030, and the percentage aged 85+ years is currently around 1.9% in Hull and is expected to increase to 2.7% by 2030.

It is also estimated by 2030 there will be approximately 50,900 people aged 65+ years living in Hull and that 3,100 of them will be aged 90+ years. Of the current GP practice list size 1% is severely frail and 3% are moderately frail.

According to the HCV STP, compared with England, Hull presents worse for obesity, smoking prevalence and smoking cessation, alcohol related admission to hospital, hypertension, and premature mortality from coronary heart disease, stroke and respiratory disease.
The number of people with a dementia diagnosis in Hull was 1,362 in 2012/13, 1,861 in 2014/15, and 2,002 in 2015/16. This has increased to 2,123 as of October 2017. This equates to 76.6% of estimated prevalence of 2,772 leaving a diagnostic gap of 649. There appears to be no association between the diagnosed prevalence and deprivation. Using the Index of Multiple Deprivation (IMD) 2015 score, Hull is ranked as the 3rd most deprived local authority out of 326 (bottom 1%).

The numbers of people who receive services are also predicted to increase, i.e. who will need help to live independently (4,633 in 2011 increasing to 6,588 in 2030), who receive a service (1,129 in 2010 increasing to 1,606 in 2030) or care provided or commissioned by the Council with Social Services responsibility (5,596 in 2011 increasing to 7,957 in 2030), and who need intensive care home care (420 in 2011 increasing to 489 in 2030).

According to local care home bed state data, as of November 2017, there are 87 providers with a residential bed capacity of c2,300. Although bed occupancy can vary both in number of voids and status (residential/nursing) there are a maximum of 357 nursing beds for individuals with dementia across 7 care homes and a minimum of 1,473 residential beds across 43 care homes for individuals with dementia. In 2014, 353 people were admitted into a permanent residential or nursing home during the year which is financially supported by the local authority. In 2016/17, 305 people aged 75 and over where placed permanently into residential care. It is anticipated that this will increase to 502 admissions to residential care 2030. Current length of stay for residential care in Hull is estimated at 2 years and 8 months.

Hull is estimated to have 1,063 people aged 65+ with learning disabilities by 2030.

There were 141 people in 2010 in receipt of direct payments and/or individual budgets. This is expected to increase to 164 by 2020 and 201 by 2030. Data is not available to show if any of these payments/budgets are for people with dementia and or their carers.

This health profile for Hull has a significant impact on the overall quality of life of citizens and in particular the demand for health, social care and other services. According to the Hull Integration and Better Care Fund Plan from 2013/14 to 2016/2017 admission rates to hospital have peaked at c300 per month for the 60 to 69 age group, 400 for the 70 to 79 age group and 600 for the 80 and over age group.

29 https://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia
Local data has been used where available to give a relatively accurate picture regarding activity relating to people with dementia. Where data has not been available, National metrics have been used to allow good assumptions to be made on Hull’s current position regarding dementia.

- **60% of dementia cases will be Alzheimer’s disease:** This would equate to 1274 cases of Alzheimer’s disease in Hull. This has an impact on prescribing costs associated with acetylcholinesterase inhibitors (ACI’s) which are often prescribed for mixed type cases too. Data from Hull’s memory Service would suggest Vascular Disease is a contributory factor to high percentage of current and new cases. Acute admission data provided by Embed Health Consortium for Hull for the period 1st October to 30th September shows that of the 2252 admissions of people with dementia 508 were coded as unspecified vascular dementia, 226 as unspecified Alzheimer’s disease and 1314 as unspecified dementia. 98% of this activity was Hull and East Yorkshire Foundation Trust (HEYFT) activity and 1% Humber NHS Foundation Trust activity (HFT) with 1% being other providers.

- **Health Equalities:** Like many other areas, including Hull’s comparators, local data suggests that the dementia diagnosis registers and service activity involving people with dementia do not reflect and represent the cultural and ethnic diversity of the City. Registers are not representative of a population that has a high and ageing migrant population for example. Post diagnosis services are accessed and attended by white British citizens. Ethnicity coding of the acute dementia activity from the same period presented above shows that 93% of admissions were white, 5% not stated. 1.5% mixed white/other and 0.5% Asian.

- **Mild Cognitive Impairment (MCI):** Although it is difficult to ascertain true MCI numbers we can be sure a significant number of people aged 65 and over will present with MCI, many of whom will go on to develop dementia. If we use the minimum 10% of over 65’s formula presented by NICE this would equate to an estimated 4500 people in Hull with MCI with up to 2700 of those going on to develop dementia.

- **2/3 of people with dementia live at home:** If we assume that most people with dementia in residential care have been identified and diagnosed then c 700 people with dementia are in residential care and 1400 are living at home. If the estimated undiagnosed are added this gives a total of c2049 people with dementia living at home. Of the 2252 acute admissions to hospital from 1st October 17 to 30th September, the source of admission for the high majority is recorded as “usual place of residence” making it difficult to ascertain how many people with dementia are admitted from a Care Home or from home. This would be a useful data capture for future monitoring and could help to demonstrate the success of Hull’s transformation plans.
• **80% of people with dementia have an identified carer:** In 2014 it was estimated 5062 people aged 65+ providing unpaid care to a partner, family member of other. This is estimated to increase to 6641 by 2030 with 3583 providing more than 50 hours per week unpaid care. If 80% of Hull’s estimated dementia prevalence of 2772 were to have a carer it would mean there are currently 2217 carers of people living with dementia. According to data\(^{30}\) accessed through the Dementia Fingertips Tool and the Dementia Catalogue, Hull had 4170 people claiming Carers Allowance as of November 2016. The current reporting system “Care First” (soon to be replaced by Liquid Logic) does not allow data capture regarding carers, however, as of April 2017, 332 carers of people with dementia on the register.

• **2/3 of people in hospital are older people and 2/3 of those will have cognitive impairment, 90% of which will be dementia:** According to HEYFTs Dementia dashboard, from April 16 to and including November 17, there have been 6305 admissions of people with dementia. Data covering the period from 1\(^{st}\) October 2016 to 30\(^{th}\) September 2107 revealed there were 2252 admissions to hospital of people with dementia totalling 16,150 bed days. The total tariff cost for these admissions was £5.653m giving an average cost per admission of £2,592. People aged between 65 and 69 recorded the highest number of admissions. The entry point for 1652 of these admissions was A & E. This admission rate is consistently around 200 admissions per month with an average length of stay of 7.2 days. Readmission rate for HEYFT for people with dementia is 18.9% as opposed to 7.6% for the Trust as a whole. 301 delay bed days were recorded for this population during the same time period but this only covered two patients both of whom were patients on HFTs Maister Lodge.

• **People living with dementia are more at risk of falls:** Falls, along with acute infections, are the main reasons someone with dementia would be admitted to hospital. Falls are a Public Health Outcomes Framework (PHOF) indicator, and from the PHOF dataset, for males and females combined, the hospital admission rate for injuries due to falls has increased over time in Hull from 2,292 per 100,000 population aged 65+ in 2010/11 to 2,820 in 2013/14. The rate in Hull was 37% higher than England in 2013/14 and was the 3rd highest out of 12 when examining comparator areas. HEYFT Dementia Dashboard data for the period April 17 to and including October 17 shows 22% of all falls in hospital involved people with dementia. The period 1\(^{st}\) October 16 to 30\(^{th}\) September 17 shows the highest cause of admission for people with dementia was disease of the respiratory system (499) disease of the genitourinary system (283) and injury (256). 84 people had delirium recorded as part of their diagnosis and 39 people had 5 or more admissions during the same period.

\(^{30}\) [https://www.nomisweb.co.uk/reports/lmp/la/1946157109/report.aspx?town=Hull]
• **72% of people with dementia have another condition or disease:** This equates to 1996 people living with dementia co-morbidities against Hull’s estimated dementia prevalence. 1% of Hull’s current GP Lists are classed as severely frail and 3% moderately frail.

• **Reduce use of antipsychotics with people with dementia:** A report written by Professor Sube Banerjee in 2009 showed Hull as the worst in the Yorkshire region for the prescribing of antipsychotics for people with dementia. With concerns regarding the data collection methodology for the report, Hull CCG conducted an audit of the prescribing of antipsychotics in patients with dementia. The audit that covered the period from November 2016 to February 2017 identified that Hull had a total of 1751 patients on the dementia register (44 out of 45 GP practices involved). Patient’s ages ranged between and including 50 years and 103 years. 173 patients were prescribed an antipsychotic giving a percentage of 9.9% which represented a reduction of 2% from 2011.

• **Maintain diagnostic rate of 67% and above:** According to the coroner’s office from 1st October 2016 to 30 September 2017, the numbers of cases where dementia is mentioned as either primary reason or contributory reason were 347 where a post mortem and Inquest was not required, 12 where a post mortem was conducted but with no inquest and 145 with an inquest. Between April 17 and November 17 there were 124 people died in hospital within 48 hours of admission, 21 of these are recorded as having dementia. HEYFT dementia dashboard reveals a mortality rate of 2.7% for the Trust with dementia being at 8.6%. To maintain Hull’s diagnostic rate of 77% and not allowing for predicted increase in prevalence would mean 504 new cases would need to be assessed and diagnosed each year. During the period from April 17 to Oct 17 inclusive, Hull’s Memory Clinic diagnosed 315 people with dementia.

Mapping exercise

Using a basic mapping template, data regarding current commissioned services were collated. This was a useful exercise in identifying dementia services however gaps in available information meant no meaningful conclusions could be drawn. As an example HEYFT services are commissioned through a tariff system where activity can be counted and costed but without meaningful outcome data it is difficult to define the value of an activity or a service. This works on the basic premise of Value = outcomes divided by costs. HFT services conversely are commissioned through a “block contract” arrangement and although activity can be identified the costs of individual activity and services cannot. Work is taking place to disaggregate costs which will then allow the value of services to be identified. Outcome data capture is more available at HFT with use of instruments such as the Recovery Star, Quality of Life tools and patient carer satisfaction and experience measures. Hull CCG commissions CHCP through a combination of seven block and tariff based contracts divided into a number of specifications. However, it is not possible to disaggregate dementia activity so again difficult to ascertain costs and therefore value.

Poor or incomplete data can also make it difficult to identify efficiencies frequently required from commissioners and providers. This could result in decisions being made from a uniformed position possibly affecting the services available and ultimately the health and quality of life of Hull’s citizens.

It is worth noting this is not an issue specific to Hull and is a fundamental issue of providing health and social care in general. Commissioning has historically focused on outputs where activity has been divided by costs to give a “unit cost”. This formula pays no attention to outcomes and so the value of an activity or service cannot be ascertained. Commissioning is now beginning to move towards an outcome and value based model which is essential when informed decisions need to be made against a background of reduced funding, increasing demand and higher expectation. Intelligent commissioning requires intelligence and supports a “fair” commissioning position.

Hull CCG and its partners recognise that effective shared data capture, measurement, analysis and learning is a fundamental action if successful transformation is to be delivered. They have demonstrated commitment to addressing this issue by making data a key feature of the local Transformation Plan, Place Plan and STP plan.

Individual and group interviews
Appendix K lists and acknowledges the great number of Hull CCG staff, partners, services and wider stakeholders who have given up their time to contribute to this review. To assist clarity, information gathered within these interviews has been analysed using a themed methodology and the key themes are presented below.

Fragmentation and variation:
Many stakeholders interviewed expressed the view that although there were many good services in Hull many duplicated their offer meaning there was potential for waste and inefficiency. Variation was acknowledged resulting in inequality and inequity where a few may receive a lot and many may not receive anything. Many professionals raised that this position increased risk and exposed Hull to safeguarding incidents.

Pre-diagnostic pathway and services:
Prevention was raised as an issue by many interviewed with several recognising the difficulty of investing in prevention when the here and now demand for services take priority. Professionals recognised that prevention is a long term action and conflicts with a short term approach for results. However, senior professionals interviewed refer to Hull’s Transformation and Place plans where prevention is a key feature. With regards to dementia is was accepted a focus on preventing/reducing vascular disease was crucial, not only to reduce dementia cases, but improve the health of the population in general. Available information, advice and education to the population were seen as key factors to influence attitudes and hopefully behaviour change. In the context of dementia, it was acknowledged that although the focused efforts by partners had resulted in an increased awareness of dementia it was difficult to ascertain the impact of this. Many raised the issue regarding stigma associated with dementia.

Post diagnostic pathway and services:
Of all the issues discussed and identified through interviews, the need for a fit for purpose post diagnostic offer for people affected by dementia was the most common issue raised. Whilst success of Hull partners delivering a diagnostic rate well in advance of the national “target” of 67% was acknowledged, it was now considered important to ensure those people were effectively cared for and supported. It was recognised this would promote independence and improve quality of life and result in the reduction of the need to rely on services. Crisis was often the trigger for intervention. Adult Social Care senior staff raised the issue of wanting to be able to respond to need proactively and “see and solve”. It was considered that services were not designed to respond in a co-ordinated
and proactive fashion. As an example increasing episodes of planned and co-ordinated respite for carers as opposed to emergency respite would indicate a proactive co-ordinated system.

**Needs of carers:**
Several professionals raised the issue of the importance of meeting the needs of carers and that any effective system has a co-ordinated offer for carers. Carer’s assessments, direct payments, personal health budgets, carer’s education (particularly the Alzheimer’s Society Carers Information and Support Programme (CrISP) and training were key topics highlighted. Building carer resilience to enable them to care well through enhanced control and choice was seen as essential.

Several interviewees reported they had previously received care and support from Admiral Nurses. Through service reconfiguration and transformation, carers support is now provided by the Carers Information and Support Service (CISS) provided by City Health Care Partnership (CHCP). The services provided by CISS were praised however, it was pointed out the CISS service was for all carers and the Admiral Nurses were specific for dementia and supported the whole family and not just the carer.

The Integrated Community Service, also provided by CHCP, provide Complex Case Managers (previously known as District Nurses and Community Matrons) who offer holistic assessment of people with dementia and their family/carers to implement a co-produced management plan to meet their physical, emotional, psychological needs, social/financial needs for example. The assessment would also identify a Care Co-ordinator for the patients care and initiate any Making Every Contact Count referrals. The case managers will also initiate Advance Care Planning to ensure expressed wishes are documented and shared with the patient’s consent. The service is offered 24 hours a day, 365 days a year via the CHCP Care Co-ordination Centre. Many raised the issue of carers “only knowing what they know” and the services offered should be accessible to all. To enhance carer resilience carers need to know how to access information, advice and support at the time when they need it.

The importance of peer support for people with dementia and their carers was repeatedly raised. The support of the local Charity Butterflies and the opportunity for people with dementia and their carer to be heard through the forum and the Voice and Influence were often praised. The Dementia Cafes provided by the Alzheimer’s Society are seen to quote one carers, as a “lifeline to people with dementia and carers”. Contract data shows the cafes are accessible, well attended and deliver high satisfaction. However, value cannot be demonstrated without capturing outcomes.
End of life:
Hull was seen as very fortunate to have access to such a high class hospice provision. Many professionals were aware of the ongoing review of Hull’s palliative care pathways and the importance of ensuring the needs of people with dementia at the end of life were considered just like any other life limiting disease. It was noted Dove House Hospice has two first class dementia suites that were currently not commissioned and unused however it was recognised such suites could support many families with loved ones at the end of life and not just people with dementia. Advance Care Planning were seen as essential tool to support for an effective End of Life pathway by promoting choice and control by recoding preferences and advanced wishes regarding end of life including place of death.

Workforce development:
Many clinical staff and partners raised the success of Hull’s innovative Dementia Academy but recognised this had somewhat waned recently and put this down to key leadership. A well educated workforce was seen as crucial for services to be effective. Humberside Police and Fire have been very effective partners, not only developing and training their own workforce regarding dementia but also contributing to wider community awareness and understanding of the disease implementing and supporting such initiatives as the Herbert Protocol and the Safe Place scheme. The role of academia and in particular the role of research was accepted as an important factor in developing a fit for purpose workforce.

Dementia Mapping was raised by several professionals as a key quality improvement tool that should be embedded into practice and should be extended beyond care and residential settings.

Collaboration and co-ordination:
Almost every person and every group interviewed raised the importance of collaboration, partnership working and the co-ordination of care and support. The importance of a seamless Primary Care and Secondary Care interface was frequently discussed with the view that every partner had an equally and important role to play in delivering an effective system. This would include the residential, domiciliary, voluntary and volunteering services.

Hull’s Dementia Collaborative was seen as a good forum for “bringing people” together but some members thought the group could and needed to be more influential especially in the design and evaluating of services. Some thought expanding this forum to include the dementia collaborative in East Riding would be useful for sharing and learning.
**User and carer engagement and involvement:**

Everyone interviewed recognised the importance of users and carers being at the centre of designing and evaluating services. The effectiveness of Healthwatch, Butterflies and Voice and Influence were seen as important factors for success. However, some thought user and carer engagement and involvement could be tokenistic and not meaningful recalling the famous Joseph Rowntree slogan of “nothing for us without us”.

**Strategy and governance:**

Most were aware of the National Dementia Strategy and the Prime Ministers Challenge on Dementia 2020 but acknowledged although strategy was important, action was more important. HEYFT has a dementia strategy covering 2016 to 2019 and HFT are currently developing a strategy. However, many stakeholders thought a Hull dementia strategy would be useful and would provide a focus and assist the galvanising of partnerships and collaborations. Many also recognised that a dementia strategy would only be useful with an appropriate governance structure that ensured grip and had accountability for delivery. Not everyone was aware of the new governance structure for integrated commissioning and were unsure of the role of Health and Wellbeing Board. Everyone recognised the need for authority and freedom to act to ensure progress was made.

**Commitment and passion:**

From a reviewer’s perspective there was no doubt the individuals and groups interviewed had an unconditional commitment and passion to make a difference to the outcomes and the lives of Hull’s citizens and for people living with the dementia and their carers and families. There was frustration for some about the speed of progress and some thought dementia provision, Hull had gone a little
backwards. However, it was accepted and acknowledged the current landscape of increasing demands, reducing resources, increasing regulation and higher expectations had a huge impact on the ability to deliver success.

**Site visits**
The reviewer visited many sites and thanks individuals and organisations for making the time to explain and demonstrate what Hull had to offer. Everyone was proud of their own services but also expressed views on how environments, systems, processes and ultimately outcomes for the citizens of Hull could be improved. Most of these views have already been presented above however they will be discussed further in the Well Pathway for Dementia section from page 25.

**Electronic Survey**
The electronic survey included 12 questions with an option to add any further feedback or ask questions to the reviewer. The 12 questions covered the five domains of the Well Pathway for Dementia and focused on the key areas of awareness, timely access for a diagnosis, care coordination, care planning and end of life. The survey was distributed through stakeholders that had contact with people with dementia and their carers and were identified mainly through the local dementia cafes and the Butterflies Group. It can be assumed the majority of responders have received dementia services within Hull. There were 23 responders who completed the whole survey. The questions, the responses and analysis can be viewed in Appendix E.

Although this survey was not a scientifically robust method of capturing data with the small number of responders providing little statistical validity, the feedback cannot be dismissed as unworthy. The analysis of responses appeared to show dementia awareness in Hull is improving compared to previous surveys however, waits for assessment and diagnosis remain variable with the numbers of people stating they had a care plan (including Advanced Care Planning) and a care co-ordinator were minimal. It is noted that every patient supported by the HFT Memory Service has an “agreed management plan” as opposed to a “Care Plan”. This may highlight the need for a common language and terminology when working in partnership or collaborating when delivering care and support for people with dementia and their carers.

Every responder took the opportunity to give additional feedback through question 12. The main issue raised was the difficulty of being able to access the right information, advice and support at the right time. Several responders detailed the huge impact the disease has had on their family and praised the support of voluntary and community sector providers.
**Engagement event**

An engagement event was organised with the specific aim of learning from people living with dementia and their carers. The feedback from the event held on 21st November 2017 builds on previous feedback obtained through similar events held in the autumn of 2016 and the spring of 2017. Appendix F presents the feedback capture from the event. This has been circulated to attendees for scrutiny to ensure the feedback captured was accurate.

**Additional communication from stakeholders**

Everyone interviewed and those who attended the engagement event were also given the opportunity to provide further comment and feedback to the reviewer through email, telephone or letter. Some took the opportunity and emails were received from carers of people with dementia, voluntary and community staff and health and social care professionals.

Most of the additional communication reinforced the findings from the one to one and group interviews presented as themes earlier. Feedback concerned the importance of obtaining accurate and timely data, carers support and carer’s education and the necessity to learn from previous projects, pilots and research.
Well Pathway for Dementia

It is worth noting and at this point that the feedback received from individuals and groups frequently raised the issue that health issues are often “too health focused” and fail to consider the impact on the wider system such as social care, the voluntary sector and communities in general. Health is more than just “clinical health” however health is vital. With dementia there is a fundamental challenge; compared to other health and disease conditions such as heart disease, lung disease and liver disease, where post diagnostic care and support is delivered by health services, dementia sits firmly in social care. This is the second challenge for transformation as health care is free at the point of delivery and social care is “means tested”. This perpetuates the opinion and feeling, that people with dementia are disadvantaged and not treated equally. This review will not resolve those challenges however; the importance of an effective Health and Social Care partnership to Transformation will be discussed further in Integrating, Commissioning and Monitoring Well (p38).

There is an abundance of evidence, guidance and support to assist commissioners, providers of services and local partnerships to transform and improve dementia outcomes. The Yorkshire and Humber Clinical Network has produced an extensive dementia resource library and again although some may feel this information is “health focused” and does not consider social care enough, it is a robust foundation to build upon and draws in the wider considerations of social care, public health and the voluntary and community sector. This review will not repeat this information but highlight the main issues and factors that would lead to a successful dementia transformation in Hull.

Preventing Well

The main aim is to minimise the risk of people developing dementia. As up to 60% of dementia cases are Alzheimer’s and 20% are vascular in origin, it is a reasonable conclusion that if cases of vascular disease are reduced then the cases of dementia will be reduced. Some research estimate as much as 50% of dementia cases has a vascular component.

Hull’s position:

With an ageing and growing population and Hull being worse for contributory health and vascular factors such as obesity, smoking prevalence and smoking cessation, alcohol related admission to hospital, hypertension, and premature mortality from coronary heart disease, stroke and respiratory disease and nothing changes, we can conclude dementia cases will continue to rise. There is a digital information portal for staff to access.

There is also an ethical perspective here and has reference to the dementia statement; “We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future”. Historically, with evidence on causation being limited and with dementia having no known cure, dementia has been overlooked from a preventative perspective. Preventing, minimising and improving vascular health is as important to the person with dementia as it is for the person without dementia.

Hull’s Dementia Action Alliance (DAA), Dementia Academy and partners have made some significant progress in raising awareness and understanding of the disease by educating staff, carers and the public about dementia and providing local businesses, professional carers and the City of Culture volunteer’s dementia information and training.

As at the end of October 2017 Hull has 3826 Dementia Friends achieved through a combination of face to face information sessions (153) and a on line resource. 35 Dementia Champions have been trained. Evaluating the impact of such numbers is difficult however it would be a rational assumption to say such action will have been a contributory factor to Hull’s diagnostic rate of 76.6%.

**Recommendations for consideration:**

It is recommended that prevention is seen as “everyone’s business” and prevention strategies and actions should be included in any future dementia transformation plan.

The standards set out in the NICE Dementia Guidance, the NICE Dementia Pathway and the resources available with Public Health England and the Centre for Dementia Prevention\(^\text{36}\) should underpin any preventative actions. Academic alliances and research should be identified and supported using the standards produced by the Organisation for Economic Co-operation and Development (OECD)\(^\text{37}\).

It is recommended that Hull develops a staff and public facing information and advice portal similar to the Dementia Roadmaps found in places such as Cornwall\(^\text{38}\), Isle of Wight\(^\text{39}\) and Doncaster\(^\text{40}\) which have been hugely successful in informing and engaging with the dementia community providing information and advice on how to “reduce the risk of dementia”.

\(^\text{36}\) [http://centrefordementiaprevention.com/](http://centrefordementiaprevention.com/)
\(^\text{38}\) [https://dementiaroadmap.info/cornwall/#.Wi_uL1VI.cs](https://dementiaroadmap.info/cornwall/#.Wi_uL1VI.cs)
\(^\text{39}\) [https://dementiaroadmap.info/isleofwight/](https://dementiaroadmap.info/isleofwight/)
\(^\text{40}\) [https://dementiaroadmap.info/doncaster/](https://dementiaroadmap.info/doncaster/)
Diagnosing Well

The aim is to ensure the opportunity for a timely and accurate dementia diagnosis that produces a care plan and a review within the first year. Any diagnostic pathway should ensure delivery of the mandate of maintaining a minimum diagnosis rate of 67%. This aim is again supported by the Dementia Statement, “We have the right to an early and accurate diagnosis, and to receive evidence based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live”.

Hull’s position:

Hull has consistently had an excellent diagnostic rate well above the National ambition of 67%. The diagnostic rate as of the end of October 2017 was 76.6%. This rate is likely to be a combination of the excellent work by partners to raise awareness of the disease, improving the diagnostic pathway and the fact that Hull has a lower than average life expectancy. The current pathway for assessment and diagnosis in Hull mirrors NICE guidance. Primary Care screen and refer suspected dementia cases to HFT’s Memory Clinic which provides multi-disciplinary assessment and diagnosis. Between April 17 and Oct 17 inclusive, the Clinic received 559 referrals and delivered an average referral to treatment (RTT) of 14.7 weeks. The service has however had a Red Key Performance Indicator (KPI) rating for assessment delivered within 8 and 14 weeks during the same period.

The clinic operates by applying the standards defined by the Memory Services National Accreditation Scheme (MSNAP) though it is not accredited. Feedback from people with dementia and their carers shows a consistent 100% satisfaction rate with the service however, feedback from some is that the clinic is geographically difficult to access. There have been 50 appointments where the patient “Did Not Attend” (DNAs) during the same period and some thought location maybe a contributing factor.

However, it is noted the service is receiving many referrals for younger people presenting with atypical cognitive issues which may also have an impact on the current DNA rate. Further analysis of DNA data is required to arrive at an informed opinion.

People with suspected dementia can also be assessed, diagnosed and treated within an inpatient facility called Maister Lodge. This is a 14 bed ward provided by HFT and serves Hull and East Riding. From April 17 to and including December 17 there have been 35 new admissions, 32 discharges and no readmissions within 30 days. There is a target of 85% for bed occupancy which has been reached for three months out of ten with an average length of stay of 95 days for the same reporting period.

Hull CCG and its partners have responded to patient and carer feedback and coupled with the national direction of travel to offer diagnostic pathways that deliver better choice and accessibility, they commenced a primary care pilot in September 2017. This pilot delivered from Sutton Manor surgery offers a diagnostic pathway within primary care for a practice defined population. A GP with special interest and skills works with secondary care specialists and the 3rd sector to assess, diagnose and offer post diagnostic support to people diagnosed with dementia and their carers. Initial feedback from an output, outcome and satisfaction perspective, is positive and the pilot has been extended to March 2018. This will provide more robust data to support future informed commissioning decisions.

**Recommendations for consideration:**

It is recommended that this review will need to be considered against the current ambitions for dementia and the impending new NICE Guidance due in the summer of 2018 with associated consultation that commenced January 2018. However, it is expected that the key outputs and outcomes will remain regarding timely access and diagnosis and co-ordinated post diagnostic offer.

It is recommended that a primary care/secondary care interface diagnostic model is commissioned. There is no defined model for Memory Services/diagnostic pathways however based on local evidence and the findings of the Memory Services Economic Evaluation\textsuperscript{42} it would suggest a primary care/secondary care interface model would deliver key outcomes and present best value for money.

It is recommended that Hull’s diagnostic pathway considers the impact of MCI and builds into its system a method of monitoring those identified with MCI. Monitoring those people with MCI will enable timely diagnosis and access to care and support if dementia does develop.

The dementia diagnostic pathway should deliver the meet the MSNAP standards and also deliver:

- A RTT of 6 weeks for 85% of referrals by 2020.
- Everyone diagnosed should have an agreed care plan that includes a Contingency Care Plan for when help and support is required and an Advanced Care Plan.
- Everyone diagnosed should be appointed a co-ordinator of care and support.
- Every care plan should be reviewed as required but within a year as standard.

Supporting Well

The aim is for people with dementia and their carers/families to access high quality health and social care delivering the standards of choice, advocacy, appropriate housing, hospital care and treatments and health and social care to all including those groups often disadvantaged and termed as “hard to reach”. Technology should be considered as standard within any commissioned provision. This aim is supported by the dementia statement; “We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it”.

Hull’s position:

Feedback from people living with dementia and their carers, in the main, is positive regarding Hull’s diagnostic pathway however, once diagnosed care and support has been found to be variable and fragmented in responding to need. Experience and outcomes in the acute setting is often poor and the residential and domiciliary care provision (including respite provision) is not fit for purpose. The results of this have been detailed previously with many people with dementia and particularly their carers experiencing crisis. This results with people with dementia attending A & E often resulting in hospital admission. Local data shows people with dementia had an average length of stay 7 and reported poor experience/satisfaction whilst in Hull’s Royal Infirmary. HEYFT has a Dementia Strategy (2016-2019) a delivery board and produces a performance dementia dashboard. An all age acute liaison service is commissioned providing HEYFT with mental health support.

Not supporting people with dementia and their carers effectively can also result in the premature need for residential care. Hull has 88 residential placements, many of which support the older and frail adult, many of whom have been diagnosed with dementia. Hull is 153rd out of 155 authorities for placing people in residential care with an average length of stay of 2 years and 8 months, 8 months more than the national average. There is no clear contract mechanism with residential care providers to ensure the needs of the population are met effectively. There are current residential voids and out of area placements. Costs for these placements vary from £96 to £408 per bed day and although these numbers are small for people with dementia (4 OOA and 6 in area independent hospitals during 2017) the expected need for this type of provision is only expected to increase. The quality of care and support is variable within care homes and they are the main source of admission to hospital for the dementia population. HFT are piloting a Care Home Liaison Service from existing resource but this has only been in operation for 8 weeks and thus too early to draw on any conclusions regarding outcomes and impact. With minimal home care and housing options (between
living at home and residential care) for people with dementia and their carers will result in a continued demand for services. Despite this position Hull is managing the needs for Continuing Health Care within budget but the wider system impact of this needs further evaluation.

Meeting the needs of carers has been consistently raised as an issue. Carers are often described as the long term care workforce and without support to build their resilience the potential result will be that the health and social care system having to meet the needs of two people rather than one. The uptake of carers assessments and direct payments/personal health budgets are low restricting choice and control, the two factors that empower individuals and have been proven to increase outcomes, satisfaction/experience and reduce funding requirements.

The current system is not designed to meet the challenge of managing the behavioural and psychological symptoms of dementia and it is these symptoms that are often the trigger and tipping point for crisis intervention/hospital admission, mental health act applications and safeguarding incidents.

The 14 beds at Maister Lodge assess and treat people suspected of having dementia and assess and treat those with a diagnosis presenting with an exacerbation of symptoms. Maister Lodge like other acute settings have high demands for beds and a length of stay increased by delays.

There is no intermediate care/step down provision to help reduce delays and the residential care provision cannot meet the complex needs presented by some people with dementia. Local data highlights Hull has too many residential beds of the type not required and not enough beds of the type that is required.

There were issues raised by general and mental health staff and services about the challenges faced when caring for and managing people with dementia who have co-morbidities. Caring and supporting a person with dementia with a physical health need adds to the increasing challenges and pressure being experienced by acute services.

Recommendations for consideration:

All the issues above have been considered and this is reflected in local Transformation Plans and within future commissioning intentions. To support people with dementia and their carers successfully will require a collaborative and co-ordinated approach. Ensuring everyone with dementia has a care plan, an Advanced Care Plan and has a co-ordinator of care, will promote joint working and effectiveness. The challenge for commissioning partners will be how to deliver this. This challenge will be discussed further in the Integrating, Monitoring and Commissioning section (p36).

It is recommended that a tiered approach to supporting people with dementia and their carers well is commissioned. It is essential the system designed and commissioned is flexible and responsive and offers a tiered approach to need. Such approaches have demonstrated better outcomes, better satisfaction/experience and significant savings.

It is recommended that a strategic and systematic approach to meeting the needs of carers. This approach must recognise the unique needs of carers of people living with dementia.

It is recommended that Liaison Psychiatry Core 24 standards are delivered. This will help improvements to outcomes and experience of people with dementia when within acute settings. Options to meet physical needs of a person on a mental health ward needs consideration too.

It is recommended that an Older Peoples Mental Health Liaison Service is commissioned. Many liaison services are all age services, but with specific Older Peoples Mental Health Liaison services have consistently demonstrated the most success in preventing admissions, promoting quality care, and supporting effective discharge. The skill set required to meet the mental health needs of older people are very different from those required to meet adult mental health needs.

It is recommended that a “Care Home Liaison Service” is commissioned. This service should be a responsive service and work closely with the planned proactive provision to be delivered to Care Homes by the Integrated Care Centre.

It is recommended that an inpatient residential and housing review takes place to consider more effective options for the assessment and treatment and placement of people suspected of and those with dementia. Meeting the needs of the more complex cases locally would reduce delays and the need for expensive out of area (OOA) and independent hospital specialist placements.

It is also recommended that along with mandatory “user and carer involvement and engagement”\textsuperscript{47}, best practice associated with “person centred care”\textsuperscript{48} the use of technology and research is embedded within any service design\textsuperscript{49}.

\textsuperscript{47} \url{https://www.england.nhs.uk/integrated-care-pioneers/resources/patient-care/}
\textsuperscript{48} \url{http://www.modem-dementia.org.uk}
**Living Well**

The aim is for people with dementia to live independent, active and safe lives in communities that understand and appreciate the needs of people with dementia and their carers. Standards involve the integrated and co-ordinated care of people with dementia and their carers and communities that promote safe and active participation in society. This is supported by the dementia statement; “*We have the right to continue with day-to-day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness*”.

**Hull’s position:**

This has been one area of the review where the voice of people living with dementia and their carers has been most useful. It is inappropriate for commissioners to tell someone with dementia they can live well with dementia. Talking and listening to people with dementia to ascertain from them what would help them to live well is essential. Connected in Care, a collaborative of professional Society of Later Life Advisors are also available to assist and advise local leaders and commissioners with forward planning.

Local people with dementia and their carers have explained the life changing challenges dementia has had on their families’ lives often leaving them feeling isolated, forgotten, discriminated or even victimised. There is an overwhelming feeling from people with dementia and their carers that a diagnosis of dementia means they are treated differently and unfairly.

People with dementia and their carers reported difficulties in accessing information, advice and support and are often passed from one person to another when they seek help.

When help and support has been available and accessible, local people with dementia and their carers have expressed how valuable it has been to them. The local Dementia Cafes, Butterflies, Age UK and the CISS all received high praise and appreciation from people with dementia and their carers.

Hull’s DAA and Dementia Collaborative work closely together and have delivered significant success. Recent initiatives such as ensuring Hull’s Taxi drivers are dementia aware and the “Mystery Shopper” scheme have increased the awareness of dementia locally. However, despite this activity and with Hull having a large number of Dementia Friends and a good number of Dementia Champions it is difficult to measure and ascertain if Hull is or is becoming more “Dementia Friendly”.
Anecdotal experiences of people with dementia and their carers would suggest there is much more that can be done to help Hull be a Dementia Friendly City.

**Recommendations for consideration:**

It is recommended that a Rights Based Approach is used to commission dementia provision using the dementia statements as a template along with such tools as Impact Assessments and Due Regard Statements to support effective and fair commissioning decisions. For people with dementia and their carers to be independent, active and feel safe in the City it is vital they are seen and treated similarly to those people without dementia.

It is recommended that the DAA utilise the “Four Cornerstone” approach to support Hull becoming regarded as Dementia friendly. The approach examines four key areas of People, Places, Resources and Networks and has had significant success in Scotland but also in towns as near as York and Bradford 50, 51, 52.

It is recommended that a clear governance structure for delivering dementia transformation is developed and communicated. For Hull to become a Dementia Friendly City it will require a co-ordinated approach and key political, health, social care and wider community leadership.


Dying Well

The aim here is that people with dementia die with dignity and in a place of choice. People with dementia are to be considered like any other person with a life limiting illness and have equal access to palliative care and hospice services. This is supported by the standards associated with palliative care, management of pain, end of life and preferred place of death. This is also reinforced by the Dementia Statement; “We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future”.

Hull’s position:

As previously stated from 1st October 2016 to 30th September 2017, there were 504 deaths involving people with dementia. Data shows, of these deaths many people are dying in hospital, many of whom are dying within days of admission. It is suspected that many of the deaths of people with dementia in hospital are people admitted from Care Homes though further work is required on data collection.

The engagement event feedback and the Electronic Survey analysis support the view that not many people with dementia have an Advanced Care Plan in place with very few people knowing what an Advanced Care Plan is.

CHCP delivers a recognised first class multi-disciplinary and co-ordinated palliative care service. However, like most services, team members often face the additional challenges providing palliative care and support with people with dementia and their carers. End of Life symptomology of pain and other physical symptoms can be managed effectively with a person who has the capacity to make decisions and choices. For people with dementia at end of life such capacity is usually not present.

The Palliative and End of Life Services operate 24 hours a day 7 days a week supported by the Health and Social Care Team and Palliative Care Co-ordinators within the hours of 9am to 5pm. The Bleep 500 nurse at Queens Centre, Castle Hill provides information/advice and organises admissions for GPs, District Nurses and Macmillan nurses and other professionals for the patient with a cancer diagnosis and who is known to the oncology service. However anyone with heart failure, lung disease or dementia for example would normally have to attend A&E or the Elderly/Acute Assessment Unit. Dove House will discuss possible admissions and advise the Macmillan nurses about any person with a life limiting condition. There is always a Doctor on call and a consultant
second on call. The service has a successful Bank Staff and volunteering provision and offers a sitting service and respite for carers however this can often be cancelled if other palliative care needs from people at the end of life take priority. The service operates a virtual ward system using technology (Cayder Board) which is continually updated by staff helping to co-ordinate provision effectively.

Hull has an excellent hospice facility delivering first class palliative care and support. Admission is based on clinical need and though people with dementia have missed out on the hospice as an option, the reason appears to be around issues of patient Capacity and Best Interest rather than diagnosis. This can cause a delay in decision making which can result in a bed being lost to another person with End of Life needs. The hospice has two suites ideal for people with dementia (and other conditions) to end their life in comfort and dignity. These suites are not currently commissioned.

**Recommendations for consideration:**

It is recommended that people with dementia and their carers have equitable access to palliative and hospice care and support capable of meeting the unique needs of this group. Hull CCG and its partners are aiming to transform and improve end of life provision, care and support and performing a similar review to enable and support transformation.

It is recommended that people with dementia are offered and supported with an Advanced Care Plan. Dying Matters have produced guidance called “time to Talk” 53 to help with this.

It is recommended that Dove House perform a self-assessment against the Hospice UK dementia principles and guidance 54 and that the Team join the Hospice UK run group, Community of Practice 55.

It is recommended that the End of Life review considers options for the use of the 2 suites with a possible option being an alternative to hospital admission for people with dementia with low grade medical problems. The emphasis would be on a palliative care intervention and family involvement helping a care package to be maintained with a minimal (as appropriate) length of stay.

It is recommended that the whole palliative care and hospice workforce is educated and trained to the appropriate level to enable effective care and support of people with dementia and their carers.

This leads appropriately into other areas not covered by the five domains of the Well pathway for Dementia but are highlighted as key components of the Dementia Well Transformation Pathway.

Training Well

The aim is to ensure the workforce have the right skills and competencies to meet the needs of people with dementia and their carers. This is supported by the dementia statement; “We have the right to an early and accurate diagnosis, and to receive evidence based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live”.

Hull’s Position:
Hull’s DAA and Dementia Academy have been innovative and successful. The partnership arrangement of bringing experienced and skilled staff together to deliver dementia training to the wider workforce and community has been a real positive for Hull. HEYFT have c 8500 staff with 50% all now trained to Level 1 of the Skills for Care dementia competencies.

Recommendations for Consideration:
It is recommended Hull partners continue to support the DAA and the Dementia Academy building on the success already achieved.

It is also recommended that DAA and Dementia Academy is formerly evaluated with Academic and Research partners to understand their impact of on service delivery and lived experience for people with dementia and their carers in Hull.

It is recommended that any training of carers needs to consider and manage the impact on the “cared for”. Many carers are unable to access training without support to enable them to do so.

It is recommended that every CCG and partnership contract aimed at delivering dementia care and support specifies that all staff involved with and working have the right core skills and received the right education and training as presented in the framework by Skills for Health and partners56.

56. http://www.skillsforhealth.org.uk/images/projects/dementia/Dementia%20Core%20Skills%20Education%20and%20Training%20Framework.pdf?Expires=1583226070&OSSAccessKeyId=xDdU5jyXa9AqytJXGQf4sVzQ&Signature=Q5dp96Ls%2f1oGxXV76kNd51J%2fto1k

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Researching Well

The aim here is for research not only to find a cure for dementia but for research to identify what works well in dementia care and support. This is supported by the dementia statement, “We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part”.

Investment in dementia research is a key component of the Prime Ministers Challenge on Dementia 2020 and has been further supported by the recent commitment by the Medical Research Council and charity partners Alzheimer’s Society and Alzheimer’s Research UK to come together to invest £250m in a new UK Dementia Research Institute (UK DRI)\(^\text{57}\). The UK DRI will lead the UK’s dementia research efforts aimed at transforming the treatment and care that people with dementia receive.

Hull’s position:
Hull has an excellent history of collaborating and producing high quality research over many years with many publications and awards. Hull University provides an excellent resource for completed research and for planning future research. HFT has a well acknowledged Centre of Dementia Research and Practice and has participated in many quality, appropriately funded, peer-reviewed, Health Research Authority-approved research projects. Appendix H provides a table of the national NIHR Portfolio research studies HFT have been involved in that relate to dementia.

Recommendations for consideration:
It is recommended that valid and robust research informs and underpins commissioning decisions as standard. Partners should recognise and build upon previous successful local research and strengthen the relationship with academia particularly with Hull University in respect of dementia research. Hull CCG and partners should also consider investing in programmes that raise the awareness of research in particular for people with dementia and their carers to be involved in dementia research, building on the work performed by HFT with the Patient Research Ambassador.

\(^{57}\) https://www.mrc.ac.uk/about/institutes-units-centres/uk-dementia-research-institute/
Integrating, Commissioning and Monitoring Well.

These elements are covered separately within the Well Pathway for Dementia however for the purpose of this review they will be discussed together here as all are parts of an effective commissioning cycle. This review has thus far focused on “what” would be required to transform Hull’s dementia provision. This section discusses the “how”.

Hull’s position:
Hull, like many areas, recognise that success will not be achieved working alone and that integration of health and social care and collaboration between the wider partners and especially with people with dementia and their carers is essential. This is demonstrated through the HCV STP, Hull Place Delivery Plan and Hull’s Integration Plan (BCF) 2017-2019 previously referred to in the introduction of this review. Dementia is one of the six priorities identified for the HCV STP Mental Health Programme.

HCV is embarking on a programme of joint work with two independent and impartial UK wide involvement networks to include people with dementia and their loved ones in planning services for the future. DEEP The Dementia Engagement and Empowerment Project (DEEP)) and Together in Dementia Everyday (TiDE) will be supporting HCV to develop ways of ensuring that the dementia work programme is co-produced with people living with dementia and family carers.

The HCV programme has recognised the value of carers and the increasing burden highlighted in this review and Initial work will include a carer development programme that will equip former and current carers of people living with dementia with the knowledge, skills and confidence to use their caring expertise to influence policy, research and practice including service transformation and redesign. By investing in TiDE HCV are committed to ensuring that carers of people living with dementia are recognised for their expertise and are treated as equal partners in the design of our future health and social care system.

Hull is currently ranked 16th in the country on the NHS and Social Care Interface and the BCF plans aim to maintain this position whilst building on the good practice through a programme of work measuring the success of Hull’s schemes (BCF).

Historically, Hull like most areas in the country, have commissioned services in isolation as presented as an example in Fig 1 below. Contracts with providers are often short time limited with providers tasked to deliver a specification focused on outputs rather than outcomes.

This system of commissioning can fail to consider the impact on the wider system. This form of commissioning can also produce issues and challenges regarding the capturing, sharing, analysing and learning from data as previously discussed. It is well documented that duplication of provision variation and health inequalities are symptoms of inefficiency caused by such silo commissioning.

Historically such commissioning has focused on service outputs making it difficult to ascertain the value of commissioned services due to the fact that outcomes are either not defined or specified. Some contracts are tariff based, which allows the cost of activity to be calculated and some are block contracts, where costs are yet to be granulated to reveal the costs of individual service lines; costs associated with dementia for example. Some contracts are a combination of tariff and block.

Monitoring of commissioned contracts can only produce, at best, performance reports that cover the specification. If the specification details outputs and time frames then that’s all that can be monitored. Monitoring can also be time consuming and costly for both commissioners and providers who again often work in isolation delivering the same information in different formats to different forums and organisations.

Fig 1.
Recommendations for consideration:

It is recommended that initially there is a three year strategic and collaborative approach locally to dementia based on an up to date and specific Dementia Needs Assessment and in response to this review. This strategic approach can galvanise people and resources to deliver a shared vision.

It is recommended that the CCG and its partners move to a value based commissioning approach focusing on outcomes along with outputs. Whether tariff or block contracts, there must be a focus on being able to identify the cost of activity. This will enable the value of activity and services to be ascertained; remembering value is outcomes divided by cost.

It is recommended that the learning from the Vanguard sites is disseminated into local practice. These sites have demonstrated that integration, commissioning and monitoring together works in delivering value for money health outcomes\(^\text{59, 60, 61}\). In summary the learning from the vanguard sites shows by working in partnership and collaborating regarding intelligence and data can result in a system that delivers value for money outcomes and improved user satisfaction and experience.

It is recommended that an Accountable Care Partnership is considered. There are several options to consider for such a system and an option appraisal of each would be required to ensure the best and informed decision was made. However, the future direction of commissioning points to the commissioning of an Accountable Care System. These are usually described as an Accountable Care Organisations (ACOs) or Accountable Care Partnerships (ACPs) and figure 2 demonstrates an example of an ACP commissioning approach.

\[\text{Fig 2.}\]


This accountable system removes the necessity of commissioning with individual providers and thus removes the associated costs of doing so. Commissioning in isolation produces repeated costs surrounding the procuring, contracting, monitoring and evaluating of individual contracted services.

A significant advantage of ACOs and ACPs is the possibility of the organisation or partnership to share back office functions, estate and importantly their data. Not only can this system create efficiencies but also improve effectiveness with the partnership focusing on delivering outcomes and not just outputs.

Hull CCG and Hull CC are currently working together to deliver a fit for purpose Care Home and Domiciliary Care offer for Hull’s citizens including people with dementia and their carers. It would make sense that this work continues and is excluded from the ACO/ACP recommended model however the work should consider the findings and recommendations of this review.

It is recommended an Accountable Care Partnership is commissioned to deliver a Dementia Service. Many CCGs in partnership with Social Care are moving away from disease defined models of operation and moving to a needs defined model. There are advantages and disadvantages of such approaches. However, as discussed previously in this review report and in the opinion of the reviewer, academics, researchers and many other stakeholders interviewed for this review, dementia is fundamentally different. It must be considered that if a solution for caring and supporting people with dementia was easily available, then surely this would have been implemented?

This review has highlighted the challenges that are currently experienced by services and include the complexity involved when caring and supporting someone with dementia and their carers including issues surrounding capacity and decision making, the behavioural and psychological symptoms of dementia, safeguarding issues and the specific issues surrounding meeting the needs of carers. An added complexity that often leads to hospital admission of people with dementia is delirium superimposed on their dementia.

Delirium is a medical emergency and requires prompt and skilled intervention. Having dementia increases the risk of developing delirium and delirium increases the risk of developing dementia.\[62\]

\[62\] https://www.dementiauk.org/delirium/
The options for dementia for Hull CCG and its partners could be:

- Do nothing and continue commissioning in isolation with individual providers.
- Work in partnership with Social Care to deliver an ACP for the Dementia Well Pathway.
- Work in partnership with Adult Social Care to deliver a system of ACPs that covered distinct parts of the Well Pathway for Dementia for example; Diagnosis (including assessment and treatment and liaison) and Post Diagnosis (Supporting Well, Living Well and Dying Well)
- Work in partnership with Adult Social Care to ensure dementia is considered as part of other Transformation Plans delivering ACOs or ACPs for example Frailty and End of Life.

It is recommended that the Dementia Service is specified to deliver the key standards of the Implementation Guide and Resource Pack for Dementia Care and delivers a tiered model of care and support for people with dementia and their carers post diagnosis. This specification, though outcome specific would detail the success of such activity as the local peer and carer support the DAA and the Dementia Academy and thus include the elements of preventing well, dementia friendly communities, training well and researching well as demonstrated in figure 3 below.

The specification would also deliver on the identified gaps within the needs assessment particularly caring and supporting groups who have not accessed dementia services for e.g. BAME groups.

![Diagram](image-url)
This ABC (Advice, Bespoke, and Complex) model represents the weighting of demand with most people with dementia and their carers for most of the time being in Tier 3 (T3) but the model has the option to flex to need of the person with dementia and/or their carer/family as required. The five Admiral Nurses* would manage the complex dementia activity in the community (3), in hospital (1) and within End of life provision (1) supported by 5 Dementia Advisors/Support workers/Wellbeing Officers. This resource capacity is suggested based on population data, demographics and national evidence nationally and with some comparators on the number and type of resource required to meet need but also deliver on the outcomes specified.

The role of Admiral Nurses has developed over the last few years. Their role has been evaluated to consistently show they are a value for money resource. Admiral Nurses now provide experts advice, care and support for the person with dementia, their carer and wider family. Evaluations have demonstrated that outcomes are delivered best when Admiral Nurses are clinically focused with managerial duties being undertaken by other colleagues. An ACP delivering a dementia service and a tiered model of post diagnostic care and support as described above would allow this.

This model would also support the ability to deliver the co-ordinator of care function and be responsible for the care plan and its review. This model would also address the issue raised by many people with dementia and their carers about “re-accessing” support.

This model does not deliver a crisis response service but a crisis prevention service. The dementia service would interface with other operational models such as crisis services, frailty and end of life as the needs of the person with dementia/carers dictate.

The CCG and partners may consider the option of “trialling” the impact of new commissioning models on a smaller scale and dementia could be a timely option and the obvious choice for such a trial with learning then being able to be applied to a larger model as required?

It would be recommended however that a long term (3 years) approach is chosen allowing the ACP to form, develop and perform. This approach would also help to prevent de-stabilisation of the system, and is a learning factor from the Vanguard sites. The ACP would be specified to deliver the key outputs and demonstrate impact on the defined outcomes presented below with a defined funding envelope.

*External non recurrent funding will be available from Dementia UK to support the provision of the Admiral Nurses.
The key outputs and outcomes for the ACP would be:

- Delivering a 6 week dementia RTT.
- Everyone with dementia has a care plan including an advanced care plan.
- The care plan was reviewed within 12 months.
- Each person with dementia has an identified co-ordinator of care.

The key measures of success would include:

- Reduced A & E attendance and hospital admission. A shorter length of stay if admission was necessary and reduced readmissions for people with dementia and their carers.
- Reduced health and social care crisis and episodes of unplanned respite for people with dementia and their carers.
- Reduction of acute service contacts by frequent users of services.
- Reduced demand on Primary Care.
- Reduced need for residential care and a shorter length of stay when required by people with dementia.
- Reduced deaths in hospital and an increased number of deaths within a place of choice for people with dementia.
- Improved satisfaction and experience of people with dementia, carers and the workforce.

The HCV STP Plan Update states “Assumption going forward – there will be no new money, we have what is currently in the system, if we attract some money this is a bonus”. Many dementia services are already commissioned to deliver such an ACP approach however it would take time to reconfigure the resource and agree with partners. Non recurrent funding focussing on delivering efficiencies could be used to allow the time for current funding to be reconfigured through potential decommissioned and recommissioning to produce a defined funding envelope for the ACP. Reducing dementia acute activity alone by 10% would deliver an efficiency saving over £500,00k based on the data presented previously in this review. With the current financial risk sharing arrangement with the CCG such efficiencies are significant for all parties.

It is recommended that a system/process is utilised like Predict-X to ensure the effective coding and tracking of dementia activity. With regards to monitoring, the identification of dementia activity throughout the system is vital. This would allow activity to be costed and value ascertained.

It is recommended that an Outcomes Based Accountability (OBA) methodology is utilised. This will, as its title suggests help ensure accountability and that outcomes are delivered. An OBA template can be seen in Appendix J which covers the commissioning cycle but ensures there is accountability and governance to deliver real value based outcomes.

Conclusion

The aim of this review was to assist Hull CCG and its partners to understand the current position regarding dementia and dementia provision in the City and understand how this position compares to legislation, national policy, guidance and what is regarded as current best dementia practice. It is hoped that this review will aid understanding and assist informed decision making.

The methodology has engaged and consulted extensively using a variety of models and compared Hull’s position to current legislation, policy, guidance and best dementia practice before making a number of recommendations for consideration. The recommendations have been set against the Well Pathway for Dementia and are for the CCG, partners and all dementia stakeholders to consider.

The key area of focus is the timely and equitable access to a timely diagnosis and co-ordinated post diagnostic care and support. Hull has an excellent dementia diagnosis rate which in turn sets other challenges on meeting the needs of those diagnosed.

The review recognises the huge impact dementia carers have in maintaining a healthy, supportive system. The importance of supporting carers to enable them to care well must not be underestimated or indeed undervalued. Meaningful engagement and involvement of people with dementia and their carers is recognised as a key action to deliver about successful design and change.

The review supports the current understanding of the CCG and wider partners that success is dependent on a strategic and system wide collaboration, partnership and integration. The expertise from legal, procurement, contracting, performance, quality and other associated colleagues should be included at the beginning of any transformation. This will influence the likelihood of timely success through effective planning, reducing risks and preventing delays.

The review highlights clearly that doing nothing and doing the same is not an option. New ways of commissioning are required to deliver effective and sustainable change.
## Appendices

### Appendix A

<table>
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<tr>
<th>Recommendation</th>
<th>Actioned by:</th>
<th>Timescale By:</th>
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<tr>
<td><strong>Preventing Well</strong></td>
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<td>It is recommended that prevention is seen as “everyone’s business” and prevention strategies and actions should be included in any future dementia transformation plan.</td>
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<td>It is recommended that Hull develops a staff and public facing information and advice portal similar to the Dementia Roadmaps referenced and found elsewhere in the country.</td>
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<td><strong>Diagnosing Well</strong></td>
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<td>It is recommended that this review will need to be considered against the current ambitions for dementia and the impending new NICE Guidance due in the summer of 2018 with associated consultation that commenced January 2018.</td>
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<td>It is recommended that a primary care/secondary care interface diagnostic model is commissioned.</td>
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<td>It is recommended that Hull’s diagnostic pathway considers the impact of MCI and builds into its system a method of monitoring those identified with MCI.</td>
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<td><strong>Supporting Well</strong></td>
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<td>It is recommended that a tiered approach to supporting people with dementia and their carers well is commissioned.</td>
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<tr>
<td>It is recommended that a strategic and systematic approach to meeting the needs of carers as a whole is delivered. This approach must recognise the unique needs of carers of people living with dementia.</td>
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<td>It is recommended that Liaison Psychiatry Core 24 standards are delivered.</td>
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<td><strong>Living Well</strong></td>
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<tr>
<td>It is recommended that a Rights Based Approach is used to commission dementia provision using the dementia statements as a template along with such tools as Impact Assessments and Due Regard Statements to support effective and fair commissioning decisions.</td>
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<td>It is recommended that the DAA utilise the “Four Cornerstone” approach to support Hull becoming regarded as Dementia Friendly.</td>
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<td>It is recommended that a clear governance structure for delivering dementia transformation is developed and communicated.</td>
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<th><strong>Dying Well</strong></th>
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<tr>
<td>It is recommended that people with dementia and their carers have equitable access to palliative and hospice care and support capable of meeting the unique needs of this group.</td>
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<td>It is recommended that people with dementia are offered and supported with an Advanced Care Plan.</td>
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It is recommended that Dove House perform a self-assessment against the Hospice UK dementia principles and guidance and that the Team join the Hospice UK run group, Community of Practice.

It is recommended that the End of Life review considers options for the use of the 2 suites with a possible option being an alternative to hospital admission for people with dementia with low grade medical problems.

It is recommended that the whole palliative care and hospice workforce is educated and trained to the appropriate level to enable effective care and support of people with dementia and their carers.

Training Well

It is recommended Hull partners continue to support the DAA and the Dementia Academy building on the success already achieved.

It is also recommended that DAA and Dementia Academy is formally evaluated with Academic and Research partners to understand their impact on service delivery and lived experience for people with dementia and their carers in Hull.

It is recommended that any training of carers needs to consider and manage the impact upon the “cared for”, with many carers being unable to access training without support to enable them to do so.

It is recommended that every CCG and partnership contract aimed at delivering dementia care and support specifies that all staff involved with and working with people with dementia and their carers in Hull have the right core skills and received the right education and training as presented in the framework by Skills for Health and partners.
**Researching Well**

It is recommended that valid and robust research informs and underpins commissioning decisions as standard.

**Integrating, commission and monitoring well**

It is recommended that initially there is a three year strategic and collaborative approach locally to dementia based on an up to date and specific Dementia Needs Assessment and in response to this review.

It is recommended that the CCG and its partners move to a value based commissioning approach focusing on outcomes along with outputs.

It is recommended that the learning from the Vanguard sites is disseminated into local practice.

It is recommended that an Accountable Care Partnership is commissioned to deliver a Dementia Service.

It is recommended that the Dementia Service is specified to deliver the key standards of the Implementation Guide and Resource Pack for Dementia Care and delivers a tiered model of care and support for people with dementia and their carers post diagnostically.

It would be recommended however that a long term (3 years) approach is chosen allowing the ACP to form, develop and perform.

It is recommended that a system/process is utilised like Predict-X<sup>60</sup> to ensure the effective coding and tracking of dementia activity.
Appendix B

Dementia In-Sight – A Review of dementia and dementia provision in Hull

Review Briefing

Introduction

The need for people to receive a timely diagnosis and better quality care and support forms part of the priorities outlined in the Prime Minister’s Challenge on Dementia. In support of this challenge the Government’s Mandate to the NHS outlines an objective to make measurable progress towards being among the best in Europe at diagnosing, treating and caring for people with dementia.

Many CCGs and service providers are seeking ways to improve the quality and costs associated with providing dementia services. Current and predicted increasing demand (through a growing and ageing population, increased public awareness and improved availability of support services), improved access and changes in workforce capacity and capability have led several to review their model of service provision. Hull CCG have commissioned Wayne Goddard, an independent clinician and commissioner to perform this review within 3 months at 24 hours per week.

Review aim

To assist Hull CCG (and its partners):

- To understand the current position regarding dementia and dementia provision in the City.
- To understand how this position compares to National policy, National Guidance and what is regarded as current best practice.
- To make informed commissioning decisions moving forward regarding dementia provision through recommendations and options for consideration.

The target audience for this document is service commissioners, although people working in or running dementia services and people living with dementia and their carers may also find the information useful.

The Review will not provide an endorsement of any particular operating model of care or commissioning model but present options for consideration by the CCG and its partners.
Review scope

In scope:
- The current Hull City population falling under the responsibility of Hull CCG
- Commissioned and un-commissioned providers of dementia services.
- Partners of Hull CCG and associated networks.

Out of scope:
- Populations not the responsibility of Hull CCG e.g. those living in Hull but have a GP registration out of the borough.
- Services not commissioned by Hull CCG and its partners e.g. Forensic Services.

Review approach

- Dementia service mapping exercise
- One to one interviews with Hull CCG colleagues.
- One to one interviews with service providers.
- Group interviews with service providers.
- Site and service visits.
- Survey Monkey.
- Engagement event.
- Offer of communication by letter, phone or email.

Review output

A report for commissioners will include:
- A description of Hull’s current position regarding dementia and dementia provision.
- A comparison of the position against current national policy, guidance and best practice.
- Practical recommendations and options for commissioners to consider moving forward regarding dementia provision.

Project methodology

- Collate a list of people and services to contact to arrange interviews and site visits as appropriate.
- Perform dementia service mapping exercise
- Perform interviews and site visits.
- Perform Survey Monkey for people living with dementia and their carers and family.
- Deliver engagement event for people with dementia their carers and family and associated stakeholders.
- Information and data collection, anticipated to be via a combination of site visits and electronic communications
- Analysis and evaluation of findings
- Draft report produced for CCG for approval and distribution.
- Draft report to stakeholders for final comment and amendment.
- Final report to CCG for distribution.
Key Milestones

The following milestones are estimates only. They have been developed with a certain amount of generosity to take into account constraints of working through the festive season:

1. Finalise and approve Review structure and documentation
2. Complete service mapping exercise
3. Approach stakeholders and services and agree involvement.
4. Set-up interviews and site visits and collate initial response from sites
5. Site visits and information gathering
7. Perform Engagement event.
8. Analysis of findings
9. Draft report for scrutiny and amendment as necessary
10. Final report sign off and distribute report

Known risks/constraints

- The Review is predicated on the principles of co-production. It is assumed that agreement will be reached with partners about the information that will be shared and that people will be available to meet the schedule needed for information gathering.
- Constraints of working through Christmas period.
- Should this not be the case, the project timetable will be at risk. This will be mitigated by all parties having access to contact details and agreeing a structure of escalation
- Keeping well within the timescale is critical to assist 2018/19 and beyond commissioning intentions and actions.
Appendix C

Review plan and timescales

Hull City Dementia Review

Work Plan

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Appendix D

Reviewer’s biography

Qualified as Registered General Nurse in 1987 working in paediatrics before commencing Mental Health Nurse training in 1989. Worked in a variety of Child and Adult Mental Health services before specialising in Older Peoples Mental Health in 1993 managing a variety of NHS services at different levels.

Educated to degree level in Education and Masters level in Health and Social care leadership. From a dementia perspective worked as a Ward Manager of an Assessment and Treatment Unit for 5 years before becoming Community Services Manager and Assistant Director for Older peoples Community Mental Health Services.

In 2009 left the provider side of the NHS and became Assistant Director for the Commissioning of Vulnerable People in Doncaster. This portfolio included Mental Health, Dementia, Learning Disabilities, Substance Misuse, Physical Disability, Secure Services and Continuing Healthcare. From 2014 became the Integrated Lead for Dementia for Doncaster working across Health and Social Care bringing people and resources together to develop and deliver a 2 year Dementia Strategy. During this time Chaired the Yorkshire and Humber Regional Dementia Leads Group and provided the commissioning voice at a National and International level being a member of NICE and Department of Health committees and working groups the most recent being the National Commissioning representative on the impending new National Institute for Health and Care Excellence (NICE) Dementia Guidance due in 2018.

From June 2017 worked as an independent commissioning advisor and commissioner for dementia providers and commissioners completing time limited pieces of work for International Consortium for Health Outcome Measurement, (ICHOM), Healthcare Financial Management Association (HMFA), Together in Dementia Everyday (TiDE) and Hull Clinical Commissioning Group.
Appendix E

Electronic Survey questions and analysis

Q1. Did you or your carer know about dementia before you realised something wasn’t quite right, or went to the GP?
52% knew about dementia before contacting their GP with concerns whilst 48% said they didn’t know about dementia.

Q2. When you noticed something wasn’t quite right, how long was it before you went to the GP, or asked for help?
35% of responders said they approached their GP within 1 month of noticing something was wrong, with 15% taking more than a month and 52% taking more than 2 months.

Q3. How long did you wait for a diagnosis of dementia?
35% waited more than a month to get an assessment for a diagnosis with 65% waiting more than 2 months.

Q4. Who gave you your diagnosis?
Most responders said that Maister Lodge or the Memory Clinic had given them their diagnosis with 1 being given by a GP, 1 being given by a hospital consultant and 1 given by another service out of area.

Q5. When you got your diagnosis did you agree a care plan?
17% of responders replied yes and 83% replied no.

Q6. Were you given a named person to contact for when you need help or support?
39% of responders said yes and 61% said no.

Q7. When you received a diagnosis, were you offered the services of the Carers Information Support Service (CISS)?
22% of responders said yes and 78% said no.

Q8. Have you ever been offered a carers assessment?
57% of responders said yes and 47% said no.

Q9. Have you or your carer ever been offered any education or training on living well with dementia?
17% of responders said yes and 83%said no.

Q10. Has it been easy to access services when your needs have changed?
30% of responders said yes and 70% said no.

Q11. Has anybody offered you the opportunity to have an Advanced Care Plan?
1 responder said yes and 21 responders said no.

Q12. Is there anything else you’d like to tell me about your experience?
Issues raised here were mainly about understanding who and how to get information, advice and support when they needed it and the huge impact dementia had on their lives. Many praised the support of the Alzheimer’s Society and Butterflies. Many reported poor experiences whilst in care services or receiving support and felt they were “left to manage”.
Appendix F

Engagement Event attendees and analysis

This event was predominantly designed for people with dementia and their carers and for stakeholders who represented the voice of people with dementia and their carers. 70 people attended the event. The event focused on confirming Hull’s current position regarding dementia before table top exercises explored “what would make Hull the best place to live with dementia” and “what would need to be done to ensure success”. The summary of the feedback is presented below using the Well Pathway for dementia as a framework.

What would make Hull the best place to live with dementia?

Preventing Well:
General health awareness wellbeing:
- Health trainers
- Health checks
- Self help
- Peer support
- Hull campaign: regular feedback, knowledge and information: online
- It can happen to you
- Explode stigma
- Engagement: everyone involved; organisations, schools, people, colleges
- Education
- Resources for preventing well.
- Understanding and accept choice.
- Positive, maximise all media for campaign: all ages: wellbeing awareness.
- Audit engagement tool.

Diagnosing Well:
- Recognising change:
- All GP’s and health professionals to be educated
- Opportunities to discuss diagnosis.
- Co-ordinating information
- Accessible recourses

Supporting well/Living well
- Clear Pathway
- Support services
- Swift interaction with carer and person with dementia.
- Named person/service – from diagnosis
- Information a co-ordination partnership working.
- Peer support
- Experts by experience
- Employers – service to support.
Dying Well:
- Care plan: including advanced wishes:
- Reduce stigma: be more open.
- Choice for place of care/dying
- Support: after care
- Support for younger families – more than just an offer of genetic testing.
- Appropriate counselling.

Additional comments:
- Support by Butterflies and Alzheimer’s Society
- 1 System for all services – up to date, everyone knows who has done what etc.
- Need a Hull Carers Advisory Group
- Need a Hull Carers strategy
- CHCP Employees survey to assist review.
- Admiral nurses – 24 hr care/support

What would we need to do to get there?
- Identify – good practice and evidence based practice. e.g. CrISP
- Deliver on agreed actions.
- Recourses – budgets – financial commitment
- Training for professionals / (carers/service users)
- Shared goal – People and carer focused
- Accountability. Agree and set achievable targets and celebrate success.
- Learn from experience, errors and improve
- Longevity and sustainability – continued commitment to commissioned service
- Invest in all – value the workforce
- Review of current services to utilise recourses effectively
- Partnership approach within services
- Listen to the people who know and need the services and utilise their experience to shape the future.
- Simple pathway – not confusing for services or service users
- Value for money – avoid duplicate services offer.
- Pilot approach – opportunity to review and amend
- Carers – clear and greater investment and care package in their own right.
Appendix G

Additional Review Resources

Clinical Commissioning Group Improvement and Assessment Framework
https://www.england.nhs.uk/commissioning/ccg-assess/iaf/

NHS England - Sustainability and transformation partnerships (STPs)
https://www.england.nhs.uk/stps/

NHS Right Care

Dementia United
http://dementiaunited.net/

Dementia Advisers
https://www.alzheimers.org.uk

Dementia Pathway
https://parkinsonsacademy.co/2017/02/15/new-dementia-toolkit

NHS Benchmarking
https://www.nhsbenchmarking.nhs.uk/

Modelling Dementia
http://www.modem-dementia.org.uk

Care planning
https://www.england.nhs.uk/mental-health/resources/dementia/
<table>
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<tr>
<th>Study Title</th>
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<td>Detecting Susceptibility Genes for Late-onset Alzheimer’s disease (AD Genetics)</td>
<td>Dr Chris Rewston, Clinical Psychologist</td>
<td>University of Cardiff</td>
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<td>Do cultural obligation, preparedness and willingness to care influence the wellbeing of family carers of people with dementia? (Caregiving HOPE)</td>
<td>Cathryn Hart, Assistant Director R&amp;D</td>
<td>University of Bradford</td>
<td>Alzheimer’s Society</td>
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<td>Social and Personal Constructs of Dementia (PRIDE WP2)</td>
<td>Dr Chris Rewston, Clinical Psychologist</td>
<td>University College London</td>
<td>Economic and Social Research Council</td>
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<td>Effective Home Support in Dementia Care: Project 2.2 Impact of different models of home support in later stages of dementia</td>
<td>Cathryn Hart, Assistant Director R&amp;D</td>
<td>University Of Manchester</td>
<td>National Institute for Health Research</td>
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<td>Evaluation of positive psychology outcome measures for use within psychosocial dementia research. (PPOM)</td>
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<td>PRIDE Intervention Development and Feasibility Study- Work Package 3</td>
<td>Prof Esme Moniz-Cook, Clinical Psychologist (hon)</td>
<td>University College London</td>
<td>Economic and Social Research Council</td>
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<td>Journeying through dementia; randomised controlled trial of clinical and cost effectiveness.</td>
<td>Dr Chris Rewston, Clinical Psychologist</td>
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<td>Dementia Carers Instrument Development: DECIDE</td>
<td>Cathryn Hart, Assistant Director R&amp;D</td>
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<td>Psychometric evaluation Achieving Quality and Effectiveness in Dementia Using Crisis Teams (AQUEDUCT):</td>
<td>Dr Clare Hilton, Consultant Clinical Psychologist</td>
<td>Nottinghamshire Healthcare NHS Trust</td>
<td>National Institute for Health Research</td>
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<td>Work Package 1 Caregivers Pro MMD: A research trial examining the utility of a website for people with memory problems and their caregivers.</td>
<td>Dr Emma Wolverson, Clinical Psychologist</td>
<td>University of Hull</td>
<td>Horizon2020, EU</td>
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### Outcomes Based Accountability Template (OBAT)

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<td><strong>What would it take to do better?</strong></td>
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## Appendix K

### Acknowledgements and table of contacts

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<tr>
<th>Contact Name</th>
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<tr>
<td>Melanie Bradbury</td>
<td>CCG Head of Commissioning</td>
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<td>Estelle Butters</td>
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<td>Gary Fee</td>
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<td>Ross Palmer</td>
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<td>Kate Memluks</td>
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<td>Lesley Windass</td>
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<td>Colin Hurst</td>
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<td>Dr Angharad (Hari) Symes</td>
<td>Primary Care and CCG Dementia Lead</td>
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<td>Peter Flannagan</td>
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